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Perspectives on quality of life of people with intellectual disabilities: The interpretation of discrepancies between clients and caregivers

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Abstract

Large discrepancies have sometimes been found between the quality of life (QOL) experienced by clients with intellectual disabilities and their QOL as described by their caregivers. Olsen and Schober (Soc Indi Res 1993; 28: 173–193) may have provided a framework useful to conceptualize such discrepancies. They suggested that lack of concordance between objective circumstances (i.e. poverty) and perceived QOL must not be treated as measurement noise, but as a source of information. They speculated on the psychological processes that underly and explain this lack of concordance; particularly processes that try to deal with the stress induced by cognitive dissonance and learned helplessness.

In this study low to moderate agreement was found between caregivers judgement of QOL of individual clients and clients' own perception of QOL. In some areas and for some clients the discrepancies indicated dissonance (caregivers are satisfied, clients are not) and in other areas and for other clients adaptation (clients are satisfied, caregivers are not). There were systematic differences between clients falling in these groups with respect to their personal characteristics and with respect to factual conditions of care. These outcomes are interpreted with respect to Olson and Schober's contentions regarding the psychological processes that underly a person's experience of QOL. The Olson and Schober framework appears to be a fruitful way to combine different sources of information regarding QOL.

Key words: People with intellectual disabilities, Perspectives on QOL, Quality of care, Quality of life

Introduction

In many discussions of the quality of life (QOL) of people with intellectual disabilities (ID) a distinction is made between two perspectives: an outsiders perspective on QOL, usually an assessment of living conditions by professionals; and the client perspective on QOL, clients' own appreciation of their daily lives [1–10]. Especially when caregivers are responsible for care around the clock, a positive association should be expected between their assessment of the QOL they provide to their clients and the QOL as experienced by the clients themselves. But is this expectation borne out in empirical investigation? Most studies thus far have found weak or moderate concordance between caregiver assessed parameters of living conditions (e.g., institutional or community care, group size, housing) and clients' perception of QOL [6, 11–14]. How can these consistent results be explained apart from pointing to measurement errors? In discussing the satisfaction paradox in people living in objective poverty, Olsen and Schober [15] provide an interesting conceptualization of concordant and discordant perspectives on QOL. According to them discordance is not to be treated as measurement noise, but as a source of information. In this paper, it will be explored whether their framework improves the insight that can be gained from combining different sources of information on QOL of clients with intellectual disabilities.

Olsen and Schober examined four possible QOL situations: (1) wellbeing: satisfaction with good living conditions, (2) deprivation: dissatisfaction with poor conditions, (3) dissonance: dissatisfaction with good living conditions, and (4) adaptation: satisfaction with poor living conditions. They speculated on the psychological processes that underly the dissonance and adaptation situations. Dissonance might be explained by presuming that people make relative judgements of their own situation. When conditions improve, for them as well as for their reference group, their dissatisfaction does not disappear. Furthermore, dissatisfaction might be a function of psychic states [16], for example depression, or of psychological traits that have little to do with objective conditions. Finally, improved conditions may lead to higher-order desires and new opportunities for criticism and dissatisfaction [17]. A different set of explanations is provided for adaptation. Adaptation might be used by individuals to reduce stress [16] in situations in which the bad conditions are hard to change and in situations where social pressure to accept the conditions is very high. To conform and to adapt is a way to deal with this so-called cognitive dissonance [18]. In the particular case of people with ID, additional explanations for adaptation might be resignation, a manner of coping with the extra stress induced by learned helplessness [19–21], high susceptibility to providing socially desirable answers, and cognitive limitations in perceiving better alternatives [22, 23].

In their framework Olsen and Schober used a factual parameter of living conditions: poverty. An objective parameter, which indicates poor living circumstances for all people with ID, is more difficult to define. Which circumstances are poor or adequate is dependent on the specific capabilities, wishes, and aspirations of individuals. It is also questionable whether a global indicator of circumstances comparable to poverty would be very informative about the factors involved in QOL. An alternative approach is to ask caregivers who know their client well to what degree they and their care organisation are able to provide their client an adequate QOL. Although this judgement is subjective because it reflects the view of individual caregivers, this judgement presents an important criterion for comparison with client-perceived QOL; because in actual practice the judgement of caregivers determines whether actions will be taken to change or improve care arrangements.

In this paper the extent to which caregiver and client perspectives on QOL are concordant will be analysed with respect to different domains and goals of life. Next both perspectives will be cast in the interpretative framework suggested by Olson and Schober and the prevalence of wellbeing, deprivation, dissonance and adaptation across the different domains of life will be examined. Finally, caregiver and client perspectives on QOL and the interpretations of Olson and Schober will be analysed as to their relation with clients' personal characteristics and with some important factual parameters of care.

Methods

This methods section starts with a discussion of the operationalization of QOL in this study, because it is pertinent to the nature of the respondents.

Questionnaire

In an earlier study a parallel QOL instrument was developed for both caregivers and clients, based on a definition of QOL along four dimensions. QOL is seen as (1) a judgment from different perspectives of the extent in which a person, given his intellectual capabilities, achieves (2) in certain domains of life (3) certain goals in life, that meet (4) certain basic norms in life and in care provision. These dimensions are described briefly. More detailed information can be found in Vreeke et al. [9] and in Janssen et al. [6].

Dimension 1: Different perspectives

QOL can be judged from a professional or caregivers perspective. Caregivers can judge QOL by considering (1) the extent to which basic needs are met and (2) the extent to which a person can achieve specific valuable goods (inter-subjective agreement about what goods are valuable is imperative: in this study an expert group was used). Because QOL of clients is studied in residential care provided around the clock, this perspective of QOL is a professional judgement of

whether care is providing adequate circumstances needed by each individual client. QOL can also be judged by persons with ID themselves (or by their parents on their behalf). From this perspective the client considers (3) the extent to which he experiences pleasure and happiness and (4) the extent to which he can realize personal wishes and aspirations in life.

Dimension 2: Domains in life
In the literature the domains of life are defined in divergent ways [1, 3, 7, 8, 25–30]. In this study they were categorized into seven domains (physical, personal, material, relational, recreational, school/work and participation in society) and 21 subdomains (for example mental health, identity and religion in the personal domain). Life may be exhaustively subdivided into these domains and sub-domains [31].

Dimension 3: Goals in life
On the basis of mission statements of Dutch care facilities and parents' organizations, other instruments measuring QOL, and the literature just mentioned, five main goals in care provision were identified: development, freedom (self-determination, autonomy), physical and social integration, physical and emotional safety and a general quality-of-life goal related to the domains of life and not associated with the other four goals.

Dimension 4: Norms in life
In the attempt to achieve these goals in all the domains of life, the paradigm of modern care provision points to an adequate combination of personalization and normalization. Mere normalization is not enough, according to Mansell and Ericsson [29]. If asked how much development, integration, freedom and safety should be facilitated, the answer would be: as normal as possible but appropriate to the personal needs of the particular individual.

Next the concept of QOL was tentatively operationalized by cross-sectioning the dimensions and filling in the resulting 105 cells (5 goals and 21 subdomains) with plausible items about normalization and personalization. A group of experts with different perspectives on care (parents, professional caregivers, management and a governmental inspector) was asked to systematically discuss these items, to reach inter-subjective agreement and to complete this operationalization of QOL. The result was a very detailed instrument: two questionnaires both with approximately 300 items, of which 212 were parallel items, formulated from a caregiver perspective (Are the needs of this individual client realized? Is access to valuable goods realized for this client?) and from a client perspective (Are you satisfied? Can you realize your aspirations) respectively. An example in the caregiver version: 'This client gets individualized (personalized and normalized) training in using public transport'. Professional caregivers answer by means of a 5-point-scale, from 'fully realized' to 'not realized at all'. In the clients version the parallel item is: 'I am satisfied about the training I get in using public transport'. The person with ID (with help of his parents or a parent on his behalf) answers by means of a 9-point-scale, from 'yes, definitely' to 'not at all'. A 9-point-scale was used in order to maximize variability in scoring (cf. Cummins [32]). In both versions 'not applicable' was an option, if the specific issue asked for was beyond the capacity of the client (e.g. client would never learn to use public transport because of his profound ID). This non-applicability option was left open, because QOL is defined as a relative judgement ('*given his intellectual capabilities*'), in order to assure that people with profound ID can also be found to experience high QOL.

A pilot study was done with a random group of 355 people with ID living in three residential facilities (mean age = 38, SD = 15, with a range from 4 to 81; 62% male, 38% female; 16% profound: IQ below 20, 22% severe: IQ between 20 and 35, 52% moderate: IQ between 35 and 50, 10% mild disability: IQ between 50 and 70; mean number of people in a single group home: 10 with a range from 2 to 14). This pilot study provided evidence for the validity and reliability of the QOL instrument. The factor analysis replicated the *a priori* domains of the model, and in the clients version of the instrument high and significant correlations were found between the specific items and general judgements of QOL. With respect to the caregiver version of the questionnaire, agreement between caregivers was studied in an selected group of 62 clients. For every client a different pair of caregivers completed the questionnaire. In the seven domains of life high agreement between the

pairs of caregivers (difference of the mean <1 scorepoint) was found for 67–95% of the clients (average 82%) [33]. In a study with 668 clients the amount of data was reduced by developing scales. For the caregivers version 17 scales were found with coefficient α varying from 0.80 till 0.98 and for the clients version 20 scales (coefficient α 0.73 till 0.97) that all largely matched the *a priori* theoretical model [9, 10].

Sample

A group of eight typical Dutch residential facilities, each 200–400 clients, with well trained caregivers (3–4 years of professional training after finishing high school) participated. The living units had an average of nine clients for the most part situated on the grounds of the facilities. Administrators were asked to select at random 100–150 clients. The questionnaires were distributed to the caregivers by our contacts in the facilities. The caregivers advised whether or not the clients themselves could complete the instrument. If not, the clients version including a pre-stamped envelope was sent to the parents. For this random group of 973 clients at least one of the versions of the instrument was completed by personal caregivers (response 92%) or by clients (response 63%; non-response occurred mainly because of lack of time, health problems, holidays, problems with the Dutch language or age of parents). For the present study both versions of the instrument had to be filled out, which yielded a subset of $n = 539$. The mean age of the clients was 37 ($SD = 15$ with a range from 8 to 82; the youngest client who himself filled in the questionnaire was 23 years of age); 58% were male and 42% female; 82% were in residential and 18% in community care (mean group size 9; range 1–18). According to the files the level of their disability, usually based on standardized IQ tests, was profound (15%), severe (21%), moderate (58%) and mild (6%).

The proxy problem

Persons with ID completed the clients' version of the questionnaire or, when they were not able to do so, it was filled in with the help of parents or by parents on their behalf. In Vreeke et al. [10], Resnick et al. [33] and in Janssen et al. [6] as well as in the present study this so-called measurement by proxy occurred in 90% of the cases. In this population proxy responding is inevitable and consonant with other studies measuring QOL [6, 14, 32, 34, 35]. The 90% rate might be higher than in other studies because of the lower level of functioning of the samples. The proxy problem deserves special attention. Like Cummins [32], McVilly et al. [14] stated that 'overall research findings to date indicate a need for caution when interpreting proxy-based data' (p. 21). McVilly et al. suggest that this statement holds particularly when staff members are used as proxies. People with moderate, severe and profound ID have moderate to profound problems in communicating their perceptions of life. This means that for them a (golden) standard for validation research is not available. Having said this, the question arises whether parent–proxy assessment of QOL really taps the subjective experience of the clients on issues where parents were not familiar with their child's feelings about the situation. Parents might in fact misrepresent actual experienced QOL (cf. Cummins [32]). Another instance in which estimation by proxy of subjective QOL could form an impediment is in cases where the personal values of the proxy respondent might slip in unwittingly, for instance in the sub-domain sexuality. It is evident that it can be difficult for proxy respondents to keep a clear distinction between their own values and standards and those of the clients themselves. Results showed that more parents, as opposed to professionals, judged the sexuality item to be 'not applicable' for their son or daughter.

On the whole the proxy problem may not be decisive. Aben and Van den Bergh [36], using the QOL version of the instrument, compared parents' judgements of their child's satisfaction with the judgements of the clients themselves using in-depth interviews. They concluded that parents could make adequate judgements of their child's opinions. But, analogous to the results of Reiter and Bendov [31], Aben and Van den Bergh found that parents have some specific difficulties in adequately reflecting their child's dissatisfaction with respect to freedom/independence. The clients themselves are more dissatisfied with even minor deficiencies in autonomy. In addition parents tend to overestimate their child's dissatisfaction with respect to discontinuity and instability in the team of professional caregivers. McVilly et al. [14],

comparing the concordance between on the one hand proxies and non-handicapped persons and proxies and handicapped persons on the other found that close relatives can make adequate judgements of clients' perceptions of QOL if a standardized approach is used. They found over- and underestimation of ratings by close relatives used as proxies to be minimal. In the present study close relatives are used as proxies and also a standardized instrument is used.

Data analysis

A decision is made to average the scores within each sub-domain to obtain scale scores. Also the scores within each goal were averaged to obtain scale scores on each goal. Scores across the questionnaires were averaged to obtain an overall QOL score. As a consequence of the relative definition of QOL ('…*given his intellectual capabilities*…'), in many cases in which the skills asked for in the individual items were beyond the cognitive or physical capacities of the clients with more profound ID, a 'not applicable' was obtained. The domain score, the mean of valid items belonging to a single domain, was skipped if the respondent had more than 40% missing or 'not applicable' scores on the items in that domain. Using this criterion, an acceptable number of items indexing each domain was retained. Listwise deletion of the 'not applicable' scores at the item level was not an option, because it would eliminate the clients with the more profound levels of ID. Moreover, in analyzing the 'not applicable' responses it was found that in most cases clients and professionals agreed on this response, implying that the summed domain scores remained to be comparable.

The distributions on the majority of the items were positively skewed, indicating that for these items most respondents were satisfied. In order to handle this skewness in statistical analyses the original item scores were dichotomized based on the qualitative descriptions of the scorepoints. For the caregivers version 'high' (original scores 4, 5: 'fully or mostly realized') and 'low' (1–3: 'partly, hardly or not realized') and for the clients version into 'high' (original scores 7–9: 'completely, very or just satisfied') and 'low' (1–6: 'a little bit' to 'certainly not satisfied').

Apart from analysing data on the level of individual items, sub-scales, and total QOL, the data were also analysed using the Olson and Schober's framework. 'Wellbeing' is represented by the high–high scores (both caregivers and clients score high), 'deprivation' by the low–low scores (both caregivers and clients score low), 'dissonance' by the high–low scores (caregivers score high, clients score low), and 'adaptation' by the low–high scores (caregivers score low, clients score high).

Results

The first question concerned the extent to which caregivers and client's perception of QOL coincide with respect to the different domains and with respect to different goals of life. Because of the different raw scores in both versions of the instrument Pearson correlations were used instead of κs. As can be seen from Table 1, the agreement is moderate at best. In 17 of the 21 sub-domains of life, the correlation is below 0.30, which is regarded as the border between low and moderate effect sizes [37]. With respect to the goals, agreement is somewhat higher, but remains within the moderate range (below 0.50).

Similar results were obtained when the dichotomized scores on the individual items were cross-stabulated. In only 77 of the 196 items (39%) for which κ could be analysed the κ was significant (Table 2). The percentages agreement, however, provided a somewhat different picture. Consistent with the positively skewed distributions, most often the agreement was on high QOL (Table 2: column wellbeing). The prevalence of wellbeing, deprivation, dissonance and adaptation across the different domains of life was examined, using Olson and Schober's framework. To identify which items indicated significant amounts of wellbeing, deprivation, dissonance and adaptation among clients, items were designated to each group based on the percentage of clients who fell into this group. Taking wellbeing as the norm (as confirmed by the skewed ratings of the respondent), a particular item was classified as a wellbeing item if 80% or more of the clients fell in this group, meaning that professional and client scored high on QOL with respect to this particular aspect of life. A particular item was classified as

Table 1. Pearson correlation[a] between mean item scores in (sub)domains in caregivers and clients' QOL

Domain and subdomains	Pearson correlations	N
Physical domain		
1 Health	0.09	348
2 Physical fitness	0.25*	347
3 Food/drink	0.42*	222
4 Mobility	−0.01	96
5 Sexuality	0.15	82
Personal domain		
6 Mental health	0.18*	285
7 Identity	0.27*	445
8 Religion/vision of life	0.29*	60
Material domain		
9 Housing	0.32*	482
10 Possessions	0.27*	268
11 Housekeeping	0.20*	228
12 Environment	0.08	427
13 Transportation	0.64*	25
Relations		
14 With professional caregivers	0.12*	455
15 With family	0.06	494
16 With others	0.26*	186
Recreation		
17 Recreation	0.30*	391
Work etc.		
18 Work	0.09	22
19 Education	0.26	18
20 Daily activities	0.15**	229
Participation society		
21 Participation society	−0.30	33
Goals		
22 General QOL	0.26*	407
23 Freedom	0.31*	174
24 Safety	0.08	144
25 Integration	0.36*	222
26 Development	0.48*	57

One-tailed: * $p < 0.01$; ** $p < 0.05$.

[a] One-tailed tests: especially when caregivers are responsible for care around the clock, a positive association should be expected between their assessment of the quality of life they provide to their clients and the quality of life as experienced by the clients themselves.

deprivation, dissonance or adaptation if 20% or more of the clients fell in this group. Because of the 80–20 criterion some items could not be classified. (Table 2: The complete item by item results of this classification procedure are available on request from the first author). This somewhat arbitrary 80–20 criterion was based on the inspection of the score distribution, which showed that using a 50–50 criterion only wellbeing items could be identified (74% of all items) and only 2% of the items fell in the other three categories and using a 90–10 criterion only 4% of the items fell in the wellbeing category. The 80–20 criterion therefore seems optimal to examine the informational value of the different categories. This criterion should, however, be kept in mind when interpreting the data.

Wellbeing is experienced by people with ID with respect to the following aspects of life (see Table 2):

1. *Basic issues in health care*: adequate basic medical and dental health care that is adequately supervised by professional caregivers; good basic hygiene and diets (if needed).
2. *Basic issues relating to the attitude of professional caregivers*: warm, supportive and nonpatronizing professional caregivers, who understand the client's particular way of communicating, feelings, problems and wishes, who facilitate awareness of handicap as well as self-care and self-help skills, create stability and predictability of life, pay attention to safety in and around the house, and facilitate contact with the family and voting at elections.
3. *Basic issues in the material domain*: pleasant, safe recreational facilities in and around the house, personal possessions and suitable transportation facilities.
4. *Basic facilities for paid labour and for organized non-paid daily activities*: safe, supervised and non-threatening facilities that match clients' capacities.

People with ID experience *deprivation* with respect to the following aspects of life:

1. *Issues that are related to the structure of the care facility* (*with consequences for autonomy and integration*): absence of recreational activities with non-handicapped people; restrictions on meeting people from outside, centrally organized services (food, transportation), limited say in the menu, in meal times, in daily activities and in choice of fellow residents.
2. *Issues of privacy*: visitors come in unannounced; absence of sound insulation in rooms.

Table 2. percentage of items with significant κ's and with categorisation in the four Olsen and Schober categories for the (sub)domain of the questionnaire

Domain	N items	% items κ signif.	Wellbeing	Deprivation	Dissonance	Adaptation
Physical domain						
Health	19	26	36	0	21	16
Physical fitness	13	23	0	8	31	31
Food/drink	14	21	21	21	57	0
Mobility	7	14	0	0	14	43
Sexuality	4	25	0	0	25	25
Personal domain						
Mental health	14	14	29	0	7	43
Identity	12	58	17	0	17	8
Philosophy of life	6	33	0	17	17	33
Material domain						
Housing	14	71	14	14	14	29
Possessions	11	55	18	0	36	18
Housekeeping	6	50	17	0	17	17
Living environment	6	33	50	0	0	33
Transportation	6	50	33	17	0	17
Relational domain						
With caregivers	11	36	55	9	9	27
With family	4	50	25	0	0	25
With others	12	33	17	17	25	8
Recreation	13	77	15	23	46	23
Activities						
Work	6	0	33	0	17	17
Education	–	–	–	–	–	–
Daily activities	14	50	29	14	21	14
Participation in society	4	50	25	0	0	0

3. *Specific issues*: limited training in non-verbal communication, limited facilities for independent use of public transport, issues of discontinuity of personnel, limited scope for caring for pets.

People with ID experience *dissonance* with regard to the following aspects of life:

1. *Almost all issues of autonomy*: dissatisfaction with the lack of freedom of choice with regard to exercise activities, sports and games, use of alcohol, cigarettes and snacks, keeping pets, inviting people from outside for dinner, going out for dinner or shopping from time to time; dissatisfaction with limited say in chores and paid or unpaid work, with the limited scope to furnish one's own room, to trade, give away or share possessions; dissatisfaction with having to inhibit sexual activities and with the limits imposed on personal life style.
2. *Safety issues* (*in the material and the relational domain*): dissatisfaction with the control of allergenic substances, the adjustment of the house to physical handicaps, the protection against harmful others and protection of possessions; dissatisfaction with the availability of physiotherapy, with clearness of intervention for self-injurious behaviour, with help for different bodily positions during the day, with training to chew well; dissatisfaction with the stability of the team of professional caregivers.
3. Dissatisfaction with opportunities for training in social and communicative skills.

Adaptation is experienced by people with ID with regard to the following aspects of life:

1. *Issues related to development*, *training and therapy*: scope for learning alternative ways of communication, coping with stressful circum-

stances, talking about emotional and religious matters, handling money, managing household and working skills and using public transport.
2. *Issues of integration in the recreational domain*: opportunities to meet non-handicapped people at home, at work and during sports and to visit family members.
3. *Issues of housing*: kitchen facilities, individual temperature regulation, privacy in bathroom and toilet, safety for mobility-restricted persons in and around the house, and sound insulation.
4. *Professional caregiver*: the availability of and free choice for a personal caregiver, who knows the client well, provides particular attention and with whom clients can speak confidentially.
5. *Specific issues*: reactions to self-injurious behaviour, evaluation of medication, protection against sexual abuse and documentation of life history.

As to now these results are all descriptive and summarize the concordant and discordant perceptions of QOL in the typical Dutch facilities. In the discussion section these results are discussed in more detail as to explanations for the differences between these aspects of QOL using the conceptualizations of Olsen and Schober.

The next question concerned the associations between on the one hand the Olson and Schober categories, and on the other some factual parameters of care and the personal characteristics of clients. These relations were explored using correlation analyses (two-tailed significance tests). The guiding principles in Dutch care provision are community care, small-scale living groups, availability of own rooms, continuity in professional staffing, and opportunities for paid and unpaid work. As shown in Table 3, almost all these factual issues are moderately or highly associated with caregivers QOL and not or at most moderately with clients QOL [37], implying that unlike professionals clients can be satisfied or dissatisfied irrespective of the factual care. The associations of personal characteristics with QOL are less distinctive. Clients' level of functioning, challenging behaviour, psychological problems are associated with both caregivers' and clients' QOL.

Finally the association between the Olson and Schober categories and characteristics of clients and factual care were examined, using the mean score on all items, which were dichotomized with the same cut-off scores mentioned in the data analysis. Table 4 shows that, except for gender, all the personal characteristics of clients are significantly related to the Olsen and Schober categories. When analysing the homogeneity of groups in the posthoc tests (Waller–Duncan was chosen because of dichotomization of the skewed data and the large sample), clients' assessment of QOL appears to make the difference, indicating that personal

Table 3. Correlations between personal characteristics of clients, care issues and QOL (mean of all items)

	Caregiver QOL	N	Client QOL	N
Personal characteristics clients				
Age	0.05	497	0.21*	495
Gender	0.06	524	0.04	522
Level of functioning	0.59*	317	0.34*	315
Challenging behaviour	−0.26*	367	−0.23*	365
Psychological problems	−0.19*	465	−0.21*	463
Length stay in care	−0.10**	504	0.07	504
Care issues				
Institutional/community care	0.52*	539	0.24*	537
Size living group	−0.33*	520	−0.07	518
Own room	0.42*	537	0.18*	535
Own personal caregiver	0.42*	537	0.18*	535
Continuity in caregivers	0.43*	533	0.17*	531
Opportunity for paid work	0.28*	94	0.17	94
Opportunity for unpaid activities	0.36*	439	0.11**	437

Two-tailed: * $p < 0.01$; ** $p < 0.05$.

Table 4. Waller–Duncan *post-hoc* tests with the personal characteristics of clients and care issues in Olsen and Schober's categories (1. wellbeing, 2. deprivation, 3. dissonance, and 4. adaptation)

	O&S	*N*	*M*	SD	DF	*F*	*p*	Groups
Personal characteristics clients								
Age	Wellbeing	99	39.6	14.36	3	5.8	0.00	4.1–2.3
(years)	Deprivation	199	35.6	13.5				
	Dissonance	114	33.1	13.6				
	Adaptation	83	40.4	17.5				
Gender	Wellbeing	105	1.42	0.50	3	1.6	0.20	None
(1 = man; 2 = woman)	Deprivation	214	1.38	0.49				
	Dissonance	119	1.45	0.50				
	Adaptation	84	1.51	0.49				
Level of functioning	Wellbeing	64	7.42	1.40	3	34.8	0.00	1.3–4.2
(1–9)	Deprivation	127	5.16	1.66				
	Dissonance	73	6.86	1.51				
	Adaptation	51	5.67	1.94				
Challenging behaviour	Wellbeing	95	0.53	0.77	3	3.4	0.02	2.3–4.1
(0–1)	Deprivation	191	0.82	0.75				
	Dissonance	105	0.80	0.86				
	Adaptation	72	0.69	0.76				
Psychological problems	Wellbeing	95	1.36	0.48	3	5.9	0.00	2.3–4.1
(1–2)	Deprivation	191	1.62	0.49				
	Dissonance	105	1.51	0.50				
	Adaptation	72	1.51	0.50				
Length stay in care	Wellbeing	101	18.00	14.32	3	4.3	0.00	4.2–1.3
(years)	Deprivation	210	18.92	10.64				
	Dissonance	113	14.41	12.21				
	Adaptation	80	19.86	12.61				
Care issues								
Institutional/community care	Wellbeing	110	1.44	0.50	3	51.6	0.00	1.3–4.2
(1–2)	Deprivation	218	1.02	0.13				
	Dissonance	122	1.34	0.47				
	Adaptation	87	1.03	0.18				
Size living group	Wellbeing	105	8.32	2.81	3	14.8	0.00	4.2–1.3
(including client)	Deprivation	212	9.70	2.25				
	Dissonance	119	8.32	2.84				
	Adaptation	82	9.99	2.10				
Own room	Wellbeing	110	1.92	0.28	3	31.8	0.00	1.3–4.2
(1–2)	Deprivation	215	1.53	0.50				
	Dissonance	121	1.88	0.33				
	Adaptation	87	1.69	0.46				
Own personal caregiver	Wellbeing	109	4.47	1.10	3	26.4	0.00	1.3–4.2
(1–5)	Deprivation	217	3.20	1.54				
	Dissonance	122	4.20	1.35				
	Adaptation	87	3.47	1.41				
Continuity caregiver	Wellbeing	109	4.44	0.86	3	32.2	0.00	1.3–2.4
(1–5)	Deprivation	215	3.44	1.10				
	Dissonance	120	4.16	1.04				
	Adaptation	87	3.44	0.96				
Opportunity paid work	Wellbeing	36	4.75	0.84	3	2.1	0.10	None
(1–5)	Deprivation	14	3.79	1.48				
	Dissonance	37	4.30	1.49				
	Adaptation	7	4.14	1.57				
Opportunity unpaid work	Wellbeing	86	4.80	0.67	3	17.7	0.00	4.2–3.1
(1–5)	Deprivation	184	4.03	1.28				
	Dissonance	94	4.77	0.63				
	Adaptation	73	4.01	1.32				

characteristics are particularly associated with clients' perception of QOL, as was also shown in Table 3. Wellbeing and adaptation, both categories in which clients are satisfied, are found especially in older clients, in clients with a longer history in care, and in clients with less challenging behaviour. In addition in the wellbeing group significantly less clients are found with psychological problems. In two cases however, the personal characteristics of clients revealed meaningful differences between clients' and caregivers' perspectives. Clients with the shortest and with the longest history in care are found in the dissonance and in the adaptation category, respectively. This is consonant with the hospitalization hypothesis of adaptation (see discussion). The wellbeing group also functions the best, followed by the dissonance group, then the adaptation group, and finally the deprivation group. This means that in those cases in which caregivers' and clients' QOL were different, the higher functioning individuals perceived their QOL as low, whereas the lower functioning individuals perceived their QOL as high. This is consistent with the learned helplessness hypothesis of adaptation inferred by Olsen and Schober (see Discussion).

As to the care issues, all issues (except opportunity for paid work) were significantly related to the Olsen and Schober categories. Here caregivers' QOL made the difference, once more indicating that factual care is associated with the caregivers' perspective. Deprivation and adaptation, both categories in which the professional is dissatisfied, are found in institutional care, in care with large living groups, when fewer clients have a room of their own, fewer clients have an own personal caregiver, continuity in caregivers is the lowest, and opportunities for unpaid work are limited. The adaptation to these care issues means that people with ID in residential care seem to adapt to these inadequate care issues, which is consonant with Olsen and Schobers' hospitalization and learned helplessness hypotheses of adaptation (see Discussion). The reverse was found for the wellbeing and dissonance categories, both categories in which the professional is satisfied.

It is worth noticing that, although in general no substantial relations are found between clients QOL and the factual care issues, the Olsen and Schober framework revealed that this was true except for institutional/community care and for the continuity in caregivers. Table 4 showed a significant difference in these two care issues between wellbeing (higher score on community care, more continuity) and dissonance (lower score on community care, lower continuity).

Discussion

Using conventional measures of association, low to moderate agreement was found between caretakers' and clients' perspectives on QOL. This was true with respect to the various life domains and goals, and applied even more strongly at the detailed level of individual QOL issues. The use of the Olson and Schober framework to interpret concordance and discordance revealed, however, that on most issues clients experience wellbeing: they are satisfied where professionals perceive the conditions as satisfactory. With respect to a minority of issues, clients experience deprivation: they are dissatisfied where professionals perceive the conditions as unsatisfactory. The low coefficients of association can be differentiated in dissonance and adaptation. On a substantial number of issues, clients are dissatisfied where professionals perceive the conditions as satisfactory (dissonance), or are satisfied where professionals perceive the conditions as unsatisfactory (adaptation).

In this study wellbeing of clients is especially evident in respect of issues of basic health care, attitudes of professional caregivers, and basic issues in the material and paid or unpaid work domains. Deprivation exists with respect to the integration of people with ID. In addition, the fact that many of the services of the institutions are centralized may be seen as a major reason why, according to clients and professionals alike, flexibility, autonomy and privacy are insufficient. Dissonance is particularly evident in issues relating to freedom and to safety and security. Clients may attach more importance to freedom and autonomy than professionals are aware of. Whatever the reference group clients may have, for many of them these issues are below standard in the residential care provided to them. Adaptation seems to exist primarily with respect to inadequate training facilities, inadequate facilitation of inte-

gration during recreational activities, insufficient availability of a personal caregiver, and inadequate housing. Many of these issues may be beyond the control of the clients. These issues refer to conditions that may be chronic. In particular, clients who are chronically hospitalized may perceive these conditions as uncontrollable. Their adaptation to such poor conditions might therefore be explained by learned helplessness [20] and by stress reduction in order to resolve cognitive dissonance [18]. Alternative explanations of adaptation might be clients wish to please caregivers, because especially clients in chronic situations are largely dependent on their care (cf. Hatton [38]) or hospitalized clients' usage of their peers as a reference (cf. Sands en Kozleski [39]).

Caregivers' and clients' QOL related differently to personal characteristics of clients and to factual care parameters. The pattern of results suggests that the caregivers' perspective on QOL is, as might be expected, more strongly associated with factual care parameters than the clients' perspective (except for institutional/community care and for continuity in caregiver). As to the personal characteristics of clients, level of functioning has the strongest association with both perspectives on QOL and makes a significant difference between all four Olsen and Schober categories. Clients in the wellbeing category appeared to be the higher functioning ones, opposed to the lower functioning clients in the deprivation category. Because of the 'not applicable' option in the questionnaires, which emphasize the comparability of QOL scores of clients of different levels, this result should be worrisome to professionals and care organizations. According to both caregivers and clients alike deprived QOL seemed to be provided to clients with a 'deprived' life.

Applying the Olson and Schober model to the relationship between both perspectives on QOL on the one hand and personal characteristics and care issues on the other yielded interesting effects with respect to level of functioning and duration of care provision. In cases of discordance, lower functioning individuals were more likely to report high QOL (caretaker report low QOL), whereas higher functioning individuals were more likely to report low QOL (caretaker report high QOL). This is also a result consistent with Olson and Schober's hypothesis that adaptation might be a way of coping with the stress of learned helplessness. Likewise, the finding that the dissonance group (caregivers high QOL, clients low QOL) was the one shortest in care indicated that hospitalisation might produce more agreement with the staff as well as more satisfaction with or resignation to circumstances that might not be satisfactory.

The interpretation of the QOL of people with ID living in institutions is hampered by various factors. One of these has to do with the fact that the clients could not answer most of the questionnaires themselves. Instead their parents completed them. This proxy problem is discussed in the methods section. The assumption is that proxies can speak for persons with ID, but this paradox cannot be solved because of the inability of persons with severe ID to express themselves: there is no golden standard. For people with severe and profound ID measurement of psychophysiological stress by means of ambulatory devices – e.g. TheVU-Ambulatory Device developed by De Geus en Van Doornen [40] – might be helpful to build their story and how they interpret crucial situations in their life. A successful pilot study is done combining online physiological measurement with naturalistic observation of client-caregiver interaction and client problem behaviours. It appeared to be possible to analyse the situations in which higher levels of psychophysiological stress were found and to advise caregivers how to improve QOL for individual clients [41].

An important implication of the findings is that discrepancies between clients and professionals can reveal meaningful issues of care and concern. Dissonance indicates that caregivers may have blind spots for some of the QOL issues that are important to clients. In this study these issues primarily concerned freedom and physical safety. Adaptation might be even more worrisome, if it is indicative of resignation and of ways to cope with the stresses induced by learned helplessness or cognitive dissonance. Adaptation might be less worrisome if the client does not show dissatisfaction because the issue is not important to him or her, even when professionals perceive the issue as unsatisfactory. In this study it was noteworthy that clients showed adaptation with respect to the unavailability of integration, insufficient availability of a personal caregiver, and inadequate housing. These issues figure prominently in de-

bates on care provision for people with ID. Either care on these issues has chronically failed, and clients show resignation or have changed their perception of this state of affairs to avoid psychological stress, or they perceive these issues as less negative or less important than caregivers do.

The data showed that discrepancies between caregivers' and clients' perception of QOL must not be primarily seen and understood as measurement noise, as in a one-dimensional model of QOL. This discordance, as an exponent of a multidimensional model of QOL, may be a major source of information for evaluating and improving care provisions. The specific issues found in the dissonance and adaptation categories may be used as an agenda.

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